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DEPARTMENT OF HEALTH

GOVERNMENT RESPONSE TO THE SIXTH REPORT OF THE HOUSE OF COMMONS SCIENCE AND TECHNOLOGY COMMITTEE: SESSION 1999/2000 CANCER RESEARCH – A FRESH LOOK

Presented to Parliament by the Secretaries of State for Health and
for Trade and Industry By Command of Her Majesty
November 2000

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INTRODUCTION

1. Cancer services are a key priority for the NHS. The publication of the NHS Plan in July 2000 and the NHS Cancer Plan in September 2000 reconfirm our commitment to improving all aspects of cancer care. The Cancer Plan sets out the blueprint for the future of cancer services: with increased investment in the cancer workforce, equipment and drugs; with improvements in prevention, screening and palliative care; and with challenging targets for reducing smoking and reducing waiting times for all stages of the cancer pathway. As a result of this investment and reform we expect that by 2010 our five-year survival rates for cancer will compare with the best in Europe.

2. Cancer research is an essential prerequisite for reducing the illness and death from cancer. Research takes many forms. Laboratory research helps us to understand the genetic and cellular changes that may produce cancer. Genetic research will provide us with opportunities not only for identifying people at risk of getting cancer but also for developing improved diagnoses and treatments. Epidemiological studies are required to identify the causes of cancer. And clinical trials are needed to find better ways of screening for cancer and improving cancer care.

3. This country makes a major contribution to all aspects of cancer research. We have world-renowned scientists, clinicians and many other high quality researchers working in centres of excellence funded by the Government, the cancer research charities and the pharmaceutical industry.

4. The Government fully recognises its prime responsibility for supporting the underpinning research on which advances in our fundamental understanding of, and approaches to treatment of, cancer and other diseases will depend. Those advances are likely to continue to come from investment in a wide range of subject areas and technologies, many of which have applications across more than one disease or condition. Accordingly, the Government announced in July 2000 further funding of £1 billion, in partnership with The Wellcome Trust, for new buildings and equipment in universities and institutes. The new Science Research Investment Fund supplements the earlier commitment of £750 million to the Joint Infrastructure Fund, again in partnership with the Trust. The Government is now also making available to the Research Councils an extra £250 million for new research activity, particularly in genomics, e-science and basic technology, supplementing the increased funding for genomics and other science which followed the previous Comprehensive Spending Review.

5. The Government has made plain that it is committed to increasing its funding for cancer research, and thereby to play a full part alongside the charities and other partners. As the NHS Cancer Plan confirmed, by 2003 we will be investing an additional £20 million each year in the infrastructure for cancer research, as well as an extra £4 million on prostate cancer research. This will mean that the Government – through the Department of Health, the Higher Education Funding Councils and the Research Councils – will, for the first time, be matching the current investment of the voluntary sector.

6. The Government acknowledges, however, that there are weaknesses in the overall pattern of cancer research in this country. High level strategic planning and co-ordination has been insufficient. The infrastructure for clinical research has been inadequate. And support for research directed at improving services has been insufficient.

7. The initial step in tackling the first of these identified weaknesses was the setting up of the Cancer Research Funders Forum (CRFF) in 1999. The CRFF – which includes the Department of Health, the Medical Research Council, the Cancer Research Campaign, the Imperial Cancer Research Fund, the Leukaemia Research Fund, the Ludwig Institute and Marie Curie Cancer Care

– has been an undoubted success. It has played a pivotal role in formulating the NHS Cancer Research Network. At the Government's request it commissioned a review of prostate cancer research, which was published in early October.

8. The next steps in strategic planning and co-ordination of cancer research must now be taken. We have, therefore, asked the Department of Health Director of Research and Development and the National Cancer Director to consult all those involved in the funding and management of cancer research and then to bring forward definitive proposals for a National Cancer Research Institute (NCRI). The NCRI will provide the focus for cancer research conducted across the country, and will provide strategic oversight of that research. It will take the lead in identifying areas where further research initiatives are indicated and are most likely to lead to progress. The NCRI will be a partnership between the Government, the cancer research charities and the pharmaceutical industry. The Government agrees with the charities and most researchers that a single, large "bricks and mortar" facility would not be optimal. The Government also considers that a separate new funding system for cancer research is not needed.

9. One function of the NCRI will be to co-ordinate research into cancer genetics in this country. Expanding knowledge of cancer genetics will have a significant impact on all aspects of cancer, including prevention. It will also address the infrastructure for clinical research into cancer, which has been inadequately supported. The Government identified this as the highest priority in a review last year, and acted by committing funds for the development of a NHS Cancer Research Network (NCRN) and this will form part of the NCRI. The NCRN will be a managed research network mapping onto the cancer services networks across the country. It will provide dedicated research nurses, data managers, medical staff sessions and information systems. The NCRN will thus produce the necessary base for clinical trials and other research, so that the quality, speed and co-ordination of clinical research will be enhanced.

10. As well as setting up the NCRI and the NCRN, the Government will continue to support research within the NHS through its 'Support for Science' funding. The Government will also support specific programmes of cancer research, including epidemiology, prevention, screening, genetics, primary care and palliative care.

11. The Government recognises that the NHS must make the best use of the results of cancer research. The Government is a founding and major funder of the Cochrane Collaboration, which contains over 50 systematic reviews related to cancer. In addition, the Government has funded evidence-based reviews to inform the 'Improving Outcomes' guidance on cancer services, and will commission further reviews to ensure that the most recent evidence informs cancer guidance from NICE.

12. New and improved approaches to cancer will also depend on the take-up of research by the pharmaceutical industry, recognised as one of the UK's strengths. The Government is determined to do what it can to make the conditions for successful interaction between industry and research generally more favourable, and in the summer it announced substantial extra funding for a range of broad initiatives. In addition, the Pharmaceutical Industry Competitiveness Task Force (PICTF) is bringing together industry leaders and Government policy-makers to identify the steps needed to strengthen the competitiveness of UK-based pharmaceutical companies. The PICTF is due to report to the Prime Minister in April 2001. A Working Group is looking at the importance of the clinical research infrastructure of the NHS.

13. The Government welcomes the Committee's report on cancer research. The Government's response is set out here, and its comprehensive strategy has been amplified in the NHS Cancer Plan, published on 27 September 2000.

Response to Recommendations

DIAGNOSIS OF CANCER

(a) We welcome the new cancer referral guidelines for the primary care sector. The Government must monitor the implementation of the guidelines and their effectiveness in supporting diagnosis of cancer in the primary care sector and referral to cancer specialists (paragraph 20).

14. The referral guidelines will be used to agree local referral criteria. An additional £20 million has been provided to support the introduction of the Government's two-week standard and some of this will be used to support and develop local audit and monitoring. Local audit will enable the appropriateness of urgent and routine referrals against the guidelines to be fed back to referring GPs. National audit will also enable GP referrals to be closely monitored against the guidelines and will inform the revision of the guidelines in the future.

15. The National Institute for Clinical Excellence (NICE) will review the guidelines in 2002/03, when at least one year's experience will be available for all tumour types.

(b) While we recognise that the introduction of the two-week standard is an important step towards improving prompt access to diagnosis and treatment, and will help to reduce patients' anxiety, the time to provision of treatment would be a more relevant standard. We recommend the introduction of challenging targets to reduce the time between GP referral and commencement of treatment (paragraph 23).

16. The Government is determined to improve access to cancer services and the NHS Cancer Plan sets out target times for waits for first definitive treatment. These are: maximum one month wait from urgent GP referral to treatment guaranteed for children's and testicular cancers and acute leukaemia by 2001; maximum one month wait from diagnosis to treatment for breast cancer from 2001; maximum one month wait from diagnosis to treatment for all cancers by 2005; maximum two month wait from urgent GP referral to treatment for breast cancer by 2002; and maximum two month wait from urgent GP referral to treatment for all cancers by 2005.

17. The implementation of these targets will require increased investment and more effective delivery of services. The NHS Plan announced that additional funding, rising to £570 million a year by 2003/04, will be made available to cancer services which will support increased staffing of cancer services and new equipment and facilities.

18. The Cancer Services Collaborative has shown that substantial improvements to waiting times can be made through streamlining the delivery of cancer services. The Cancer Services Collaborative will be rolled out by the Modernisation Agency across all cancer networks by 2003.

(c) The introduction of a fast-track system for people suspected of having cancer would increase the demand on an already over-stretched service. Thus it must be matched by the provision of a greater capacity in radiology and pathology if the management of cancer patients is to improve (paragraph 24).

19. High quality and prompt diagnosis and staging of cancer is essential to the delivery of fast, modern cancer services. Over the next five years an extra 300 pathologists and 260 radiologists will complete their specialist training. The funding for cancer services announced in the NHS Plan will mean that NHS Trusts can plan to increase the number of consultant posts for these additional specialists.

20. The National Cancer Director is working with the professions to identify ways to enable the available cancer staff to work more effectively, for example by extending the roles of some groups of staff such as nurses and radiographers. Development sites to assess the scope for new, more flexible staffing arrangements for the breast screening programme began in October 2000.

SCREENING

(d) Strong research programmes are needed to identify and develop cost-effective screening techniques for the more common cancers (paragraph 26).

21. We agree. The National Screening Committee (NSC) advises the Government on screening, and supports the commissioning of high quality research to inform the appraisal of new population screening programmes. Representatives of the NHS R&D Health Technology Assessment (HTA) programme and the Medical Research Council (MRC) sit on the NSC to ensure that screening research priorities are communicated to the appropriate funding body.

22. The Government and its partners are currently funding several relevant research projects. For example, the Department of Health and the MRC, together with cancer research charities, are funding a major trial of ovarian cancer screening. In addition, the MRC is considering a proposal for a prostate cancer screening trial, and a proposal for a trial of spiral CT for lung cancer screening. For colorectal cancer, the MRC is funding an evaluation of screening by flexible sigmoidoscopy, and the Department of Health is evaluating pilots of screening using faecal occult blood testing.

23. The MRC has a major role in developing genetic testing techniques: the most commonly used micro-array technique is based on fundamental MRC research from the early 1990s, and the MRC continues to fund this area. The MRC and the Engineering and Physical Sciences Research Council have recently expanded research programmes into imaging and image analysis. As well as evaluating and developing screening methods, more fundamental research is also needed to identify entirely new screens. The programme of MRC's newly formed Cancer Cell Unit will include studies to identify potential biological markers with potential for use in screening or diagnosis.

(e) We recommend that the Government and the National Screening Committee evaluate high speed and precise techniques with a view to commencing large-scale trials for CT cancer screening. This would require the NHS to purchase state-of-the-art diagnostic equipment (paragraph 27).

24. The NSC has asked NICE to appraise the CT scanning technique of virtual colonoscopy. This will inform advice about introducing a national programme for colorectal cancer screening, which will follow the completion of the current pilot screening programme in 2002. A decision about the NICE work programme will be made later in the year.

25. The NHS R&D Programme is funding a research project comparing virtual colonoscopy with conventional fibreoptic colonoscopy. Results should be available next spring. The NHS Health Technology Assessment Programme invited research proposals on this topic in 1998. Unfortunately, no supportable proposals were received. The Programme is actively considering the best way of taking forward this important research priority area.

26. The UKCCCR Lung Cancer Group has recently submitted a proposal for a pilot study of spiral CT screening for lung cancer to the MRC, who are currently considering it. If the MRC decide to support this trial, the Department of Health will provide substantial funding.

27. The Government is committed to tackling the past legacy of outdated equipment. We have already invested nearly £200 million for modern cancer equipment in the NHS and further investment has been identified in the NHS Plan. As a result, by 2003/04 there will be 200 new CT scanners. This investment is part of the modernisation of our cancer services.

TREATMENT OF CANCER

(f) We recommend that the Government increase the number of specialist surgeons for each type of cancer to a level where appropriate specialists perform most cancer surgery. We also recommend that it support surgical oncological research (paragraph 30).

28. There is evidence that for common cancers, such as breast cancer, patients treated by specialist teams are more likely to survive their cancer. For the less common cancers, such as stomach, pancreas and ovarian, patients who are treated in hospitals that care for larger numbers of patients with that condition are likely to do better.

29. Surgery remains the mainstay of primary treatment for many types of cancer. Cancer surgery is undertaken by general surgeons (e.g. for breast, upper gastro-intestinal and colorectal cancer), urologists, gynaecologists, thoracic surgeons, etc. We are reviewing the numbers of higher specialist trainees in general surgery again this year, taking account of the targets for improvements in cancer services as set out in the NHS Plan and the NHS Cancer Plan. With the numbers currently in training, it will be possible for the numbers of consultants in general surgery to increase by around 440 by 2006.

30. The Government is supporting a number of research projects on surgical oncology, and would like to support more. Unfortunately, only a few research proposals are received in this area relative to other cancer treatments. More high quality proposals would be very welcome. The Department of Health will be exploring ways of increasing surgical oncology research, and other research priorities, both through its own mechanisms and in conjunction with funding partners through the Cancer Research Funders Forum and through the National Cancer Research Institute as it develops. Establishment of the NHS Cancer Research Network should greatly facilitate trials of cancer surgery.

31. The MRC recognises the need to strengthen the number of people active in surgical research of all types, and has been working with the Royal College of Surgeons and the Royal College of Surgeons of Edinburgh through joint awards schemes. There are currently nine surgeons holding MRC Clinical Fellowships in cancer research.

32. The Department of Health and the Academy of Medical Sciences, together with the MRC, have developed a new Tenure-Track Clinician Scientist Fellowship scheme, in response to the Savill report of March 2000 on career structure for clinical scientists.

(g) We recommend that the Government address the service problems in the delivery of radiotherapy and actively encourage research into radiotherapy. We recommend that IMRT and 3D-CRT equipment should be made available in all cancer centres together with trained personnel (paragraph 32).

33. Central investment in radiotherapy is being made through the New Opportunities Fund initiative for cancer and through funding announced in the NHS Plan. By 2004 a total of 101 new linear accelerators – replacement and additional – will have been bought. These linear accelerators will be specified to a high level, with multi-leaf collimators and portal imaging systems, and will be capable of delivering Intensity Modulated Radiotherapy. In addition funding has been made available for three-dimensional conformal radiotherapy treatment planning computers and

radiotherapy simulation equipment. This equipment will enable complex radiotherapy treatments to be planned, checked and verified.

34. Regional capital investment programmes will be expected to incorporate strategies to ensure that cancer equipment is kept up to date.

35. The Government is already funding research into radiotherapy through the NHS and the MRC, and would welcome further high quality applications. The new NHS Cancer Research Network will enhance accrual into clinical trials across the spectrum of cancer, including trials of radiotherapy.

(h) It is unacceptable in a National Health Service founded on the principles of equity that drugs which can improve the length and quality of cancer patients' lives are only available to some of those who could benefit (paragraph 34).

(i) Nevertheless, we remain unconvinced that guidance from NICE alone will ensure national availability of recommended treatments. We recommend that the Government ensures that its follow-up procedures require all Health Authorities to provide anti-cancer treatments which are approved by NICE where the patient's consultant regards them as clinically appropriate and prescription is within the guidelines set by NICE (paragraph 35).

(j) We recommend that full additional funding of NICE-approved treatments be provided to all Health Authorities, regardless of whether an authority was already providing the treatment prior to its approval by NICE (paragraph 36).

(l) The low level of use of the latest anti-cancer drugs in the UK compared to other European Countries disadvantages cancer patients in the NHS and discourages pharmaceutical industry investment in clinical trials. We recommend that the Government reviews the arrangements for the provision of anti-cancer drugs to NHS patients to ensure that the best drugs are available, to all those patients who may benefit, as quickly as possible (paragraph 38).

36. NICE will publish authoritative, evidence-based guidance on the use of specific treatments and drugs, advising on their clinical and cost effectiveness. Over the next 12 months NICE will appraise 13 recently licensed cancer drugs so that all Health Authorities will have the benefit of expert assessment of the evidence of effectiveness and cost-effectiveness of cancer drugs.

37. NHS Trusts will be expected, through clinical governance arrangements, to promote the rapid uptake of NICE's guidance. They should ensure that it is taken fully into account in clinical decision making, and that any treatment decisions not in line with the guidance can be justified in the particular clinical circumstances of each case.

38. The additional funding for the NHS, including those for cancer services announced in the NHS Plan will mean that all Health Authorities and Primary Care Trusts will be able to meet any additional costs arising from the provision of anti-cancer drugs recommended by NICE.

39. The Commission for Health Improvement will ensure that clinical governance arrangements in NHS bodies are effective, and that any difficulties in implementing NICE guidance are promptly reported back to the Department.

(k) We see no reason why guidance from NICE on cost-effectiveness of treatments cannot be delivered at the same time as marketing approval is given. We recommend that the Government find better ways of operating NICE so that guidance on drug treatment can be issued by NICE at the same time as the granting of marketing approval (paragraph 37).

40. The consultation document "Faster Access to Modern Treatment: How NICE appraisal will work" made it clear that it was the Government's intention that guidance from NICE on the clinical and cost effectiveness of new drugs should be issued as soon as possible after marketing approval. This was subject only to the need to ensure that NICE's guidance in its final form relates to the licensed applications actually approved. In NICE's first year of operation, it was not possible to achieve this in every case since priority had to be given to guidance on a number of existing treatments – such as taxanes for ovarian and breast cancer – for which there were serious problems of unequal access.

(m) More clinical research is needed to determine the benefits that patients derive from complementary therapies. We recommend that the Government seeks guidance from NICE on the cost-effectiveness of complementary therapies for cancer care to ensure consistency of provision across the NHS (paragraph 42).

41. The Government is aware that up to one third of cancer patients in the UK find that they derive some personal benefit from complementary therapies, and recognises that many oncology units and hospices offer at least one such therapy to patients. There is no specific national NHS guidance on the purchasing of complementary therapies. It is for local purchasers and clinicians to decide how best to use their resources, having taken into account all of the available evidence.

42. Proposals for complementary and alternative medicine (CAM) research can be considered through the normal funding mechanisms of the Department of Health and the MRC. In addition, the MRC offers help to those interested in CAM studies to develop expertise in relevant research methods, and important proposals can be developed further through the MRC's trials development groups.

CANCER TREATMENT NETWORKS (CALMAN-HINE NETWORKS)

(n) We believe that cancer care networks should also provide an essential resource for clinical research and that research based on cancer networks should be given more emphasis than was evident in the Calman-Hine report itself. Clinical research should be an explicit part of the remit of both cancer centres and their associated units (paragraph 44).

43. The Government agrees entirely with this point and is firmly committed to the development of clinical research based on cancer networks. The NHS Plan announced the introduction of a new NHS Cancer Research Network (NCRN) which will be fully implemented by 2004. Its initial aim is to double the number of cancer patients entering trials within three years.

44. By 2003 we will be investing an additional £20 million each year in this new infrastructure for cancer research. The first step in establishing the NCRN is to commission a Co-ordinating Centre, and the Centre has recently been appointed.

45. The NCRN will create a world-class health service infrastructure to support cancer research. It will be the first time that we will have formal integration of cancer research at a national level. The NCRN will be a managed research network mapping onto NHS service networks for cancer care in England. All cancer service networks will be eligible to become Research Networks of the NCRN, and it is anticipated that all will do so. The NCRN will provide the dedicated research nurses, data managers, medical staff sessions, radiology, pathology, pharmacy, information systems etc needed to support high quality randomised trials of cancer treatment and other well designed studies.

46. The NCRN will: integrate research and cancer care; improve the quality, speed and co-ordination of cancer research; and increase the number of NHS organisations, health care professionals and patients participating in cancer research studies.

(o) We recommend that the National Cancer Plan, which must incorporate the development of a research ethos in cancer centres, include built-in milestones and explicit estimates for the additional capital and recurrent financial resources necessary to deliver the required elements of: Organisational change; additional specialist and support staff; equipment, and new treatments and therapeutic techniques (paragraph 52).

47. The NHS Cancer Plan has set out clearly the new arrangements for all these. Explicit milestones have been set for the development of services, and the capital and revenue funding available for these developments has been made clear.

NATIONAL CANCER STANDARDS FRAMEWORK

(p) We welcome the introduction of national guidance on improving outcomes for cancer patients and the initiatives to monitor delivery. It is, however, wholly unacceptable that delays in implementing the guidance on treatment should be the result of tardiness on the part of NICE or contrary funding decisions on the part of Health Authorities (paragraph 55).

48. The programme for producing evidence-based guidance will inevitably take time. However, improvements to cancer services as laid out in the NHS Plan and the NHS Cancer Plan will apply to all patients regardless of cancer type.

49. New funding identified for cancer services in the NHS Plan will ensure that Health Authorities have the necessary resources to implement Improving Outcomes guidance and appraisals of cancer drugs as they are issued. NHS Trusts will be expected, through clinical governance arrangements, to promote the rapid uptake of NICE's guidance. They should ensure that it is taken fully into account in clinical decision making, and that any treatment decisions not in line with the guidance can be justified in the particular circumstances of each case.

50. NICE is aware of the need, and makes every attempt, to produce guidance as quickly as is reasonably possible. An important safeguard built into NICE's appraisal process is that interested parties, including patient and professional groups as well as the companies involved, have the opportunity to contribute to the gathering of the evidence and comment on the draft guidance before it emerges. This process takes time.

51. In the case of taxanes for ovarian cancer, NICE agreed to give them very early priority in their appraisal programme. Until NICE guidance is issued, clinicians are expected to assess the needs of individual patients on the basis of evidence and guidance already available, including "Improving Outcomes in gynaecological cancer"

RESEARCH INTO THE CAUSES AND NATURE OF CANCER

(q) We are concerned that in the UK there are shortages of skilled personnel in key areas of science — such as bioinformatics. We recommend that the Government identify and remedy these skill shortages (paragraph 63).

52. The Research Councils, with the Universities, have primary responsibility for meeting the national need for highly trained researchers. The Government is making additional funding available to enable the Councils to increase stipends for research students by 23 per cent in real terms over the next three years. The Biotechnology and Biological Sciences Research Council (BBSRC) and the MRC are engaged in major reviews of their support for postgraduate training generally.

53. The Government and the Councils have recognised the case for strengthening training in bioinformatics. The MRC, working with other Research Councils and funding agencies, has been working to build up bioinformatics expertise and infrastructure in the UK since 1995, and is now the UK's largest funder of bioinformatics training. The MRC and the Engineering and Physical Sciences Research Council (EPSRC) have issued a joint call for proposals to stimulate R&D in the area, and are exploring options for the next stage of development of the European Bioinformatics Institute at Hinxton.

54. For the last six years EPSRC has run a joint initiative with the BBSRC totalling £10 million in grant support, and both Councils, along with the MRC, have increased their support for bioinformatics students at PhD and Masters' level. BBSRC has launched two summer schools to help train BBSRC supported students and research assistants in informatics. The EPSRC has funded four new bioinformatics units, providing five years' support for a chair and, in two cases, an associate lectureship.

55. The Government recognises, as do the Research Councils, that further expansion of the UK bioinformatics effort is needed, and this will be taken into account in deploying the extra money available to the Science Budget over the next three years. In addition, DTI is currently assessing the scope for future initiatives to help UK industry take up the opportunities provided by bioinformatics. This would aim to complement any initiatives supported by other funding bodies.

56. The UK also needs to be able to pay its top academic scientists competitive salaries, especially in highly competitive areas such as bioinformatics, where normal rates of pay in Universities fall well below the levels available in industry and abroad.

57. This was acknowledged in the recent Spending Review which made an extra £50 million available through DfEE to higher education institutions in order to recruit and retain top quality academic staff in an increasingly global market for people and ideas. In addition the Office of Science and Technology, working in partnership with the Wolfson Foundation and the Royal Society, are launching a fund, initially worth £4 million a year, to assist in the recruitment of up to 50 leading researchers in key areas of science, so that we can compete in the world market for the best academics.

TRANSLATIONAL RESEARCH

(r) We recommend that assessment of research quality and provision of research funding in the clinical and translational arenas take account of their long-term nature and gives due recognition to these important activities, particularly in the field of oncology (paragraph 69).

58. The Government agrees that research assessment, and research funding, need to take proper consideration of the long-term nature of translational cancer research. The original proposal for the NHS Cancer Research Network recommended that it should include up to eight Translational Research Centres. The Cancer Research Funders Forum is considering this particular recommendation in relation to the fact that many funders other than the Department of Health already fund active centres of translational research.

59. MRC policies already reflect the need to provide for stable long-term research programmes: most MRC research awards provide for five years' funding. The MRC is already working to develop, in collaboration with other funders, centres of excellence with the critical mass of scientific and clinical expertise, and supporting facilities, needed for translational and applied research. Examples include the MRC's support with other funders for translational research in Birmingham University, the new multi-million pound CRC/MRC Cancer Collaboration in Cambridge, and the £2 million award to Manchester University for research into new treatments.

The new NHS Cancer Research Network will strengthen the support for some translational research, such as early stage trials, as well as supporting large multi-centre trials.

60. Recognising and supporting collaborative efforts and networks of this sort, both in medicine and other disciplines, has been a particular concern of the recent Higher Education Funding Council for England (HEFCE) Fundamental Review of Research Policy and Funding. This review welcomed the changes to the 2001 RAE which will provide a clear mechanism for the contribution of all partners to collaborative developments such as multi-centre trials and networks to be recognised. In addition, the HEFCE has accepted the recommendation of the review that it should explore further what can be done to ensure that such collaborative endeavours and networks are properly encouraged and appropriately supported.

61. Improving investment by the private sector is also an important part of our strategy for translating advances in basic science into new diagnostics and treatments quickly. Some advances in basic research, such as the development of humanised antibodies, have led to new licensed drugs for breast cancer and leukaemia in just 15 years following heavy investment by the biotechnology sector. A third of the start-up companies formed from MRC research are working on cancer treatments, and the Spending Review 2000 has provided further funding to accelerate knowledge transfer from the University science base to privately funded ventures.

(s) We recommend that the Government and the National Cancer Director ensure that clinical research scientists working in translational research have sufficient time available, away from their NHS responsibilities, to allow them to carry out research (paragraph 70).

62. Clinical research scientists working in translational research usually hold academic appointments with a medical school as well as having clinical sessions within a NHS Trust. Medical schools work closely with their NHS colleagues to ensure that clinical scientists have sufficient time to carry out all of their duties – clinical and academic. This is in accordance with the strategic, operational and funding principles for co-operation between university medical schools and the NHS that have been promulgated by the Steering Group on Undergraduate Medical and Dental Education and Research.

TREATMENT AND CLINICAL TRIALS

(t) Increasing the number of adult cancer patients entering clinical trials must become a high priority. We recommend that the Government sets challenging and specific targets for the proportion of eligible adult cancer patients entering clinical trials for all the most common cancers (paragraph 75).

63. We agree that increasing the proportion of patients entering trials would both benefit patients in the short term, and would speed the development of the evidence base for future care. That is why we are creating the NHS Cancer Research Network (NCRN), with an aim of doubling the number of patients entering trials within three years. All existing service networks for cancer care will form part of NCRN, and the NCRN will be an integral part of the new National Cancer Research Institute.

(u) We recommend that stronger safeguards are put in place to ensure that informed consent is obtained from all patients before enrolment into a clinical trial (paragraph 76).

(v) We recommend that the Government reviews NHS procedures for obtaining patients' informed consent for participation in clinical trials, including increased use of research nurses and the voluntary sector (paragraph 77).

64. The Government regards consent as central to protecting the rights and interests of patients. The Government is aware of the serious concerns that have been expressed about obtaining consent in both clinical and research settings. In the NHS Plan, the Government indicated its commitment to ensuring good consent practice. The Government made clear that in both the clinical and research contexts it would be undertaking work with clinicians, academics and patients and their representatives with the aim of introducing changes in 2001. The Committee's recommendations will be taken into account in developing the proposals for change.

65. The Department of Health has published a consultation draft Research Governance Framework. The consultation will take place over the autumn and the Framework will be published at the end of the year. The safety and well-being of patients may be put at risk if individual responsibilities are not made explicit. It is for this reason that responsibilities, including those for ensuring that valid consent is obtained, will be made explicit in the Framework.

(w) We recommend that the Government produce and maintain a publicly accessible, comprehensive database of all clinical trials, including those funded by industry, currently recruiting patients, using *Cancernet* as a model. This will need to be advertised widely. The Government must also encourage GPs and hospital consultants as well as healthcare organisations such as community health councils to advise patients of available trials relevant to their condition (paragraph 80).

66. The Government agrees that it should promote the registration of all clinical trials on a publicly accessible database. For publicly funded trials it is working to develop systems and arrangements which would enable sponsors to register their trials themselves, allowing certain details to be collected on a meta-register through appropriate database links.

67. MRC trials co-ordinated and funded with ICRF and CRC are already on the UKCCCR register of cancer trials. All MRC trials, including cancer, are already available on the searchable Current Controlled Trials Metaregister. This provides open access to 15 registers and over 6,000 trials.

68. We are pleased to see that the ABPI are recommending to companies that they should register clinical trials undertaken in the UK, albeit retrospectively after licensing registration of a new medicine in a major market. Their arrangements are a helpful step towards the establishment of a comprehensive, prospective meta-register of clinical trials.

(x) We recommend that the Government significantly increases the numbers of oncologists in training, setting a ten-year target to ensure that there are sufficient numbers of consultant oncologists to bring patient workload into line with that in comparable countries. We also recommend that the Government ensures that, as the new consultants qualify, new academic and clinical consultant posts are created (paragraph 85).

69. The number of Consultant Oncologists (Clinical and Medical) in England is set to expand by 73% – over 300 extra oncologists – over the next five years. The National Cancer Director is working with post-graduate lead deans towards setting long-term targets for cancer specialists in the country, in discussion with professional bodies. The funding allocated to cancer in the NHS Plan will enable new consultant posts to be created in time with the expected expansion of the profession.

(y) We recommend that the level of remuneration for academic medical careers should be reviewed to ensure that they are competitive with NHS-based careers. We further recommend that, in addition to the specialist training requirement, oncologists should be encouraged to undertake a period of research (paragraph 86).

70. Clinical academics' pay is linked to NHS clinicians' pay, which is settled following the Doctors and Dentists Review Body recommendations. The timing and implementation of settlements are matters for the university employers. These settlements tend to be higher than those of non-clinical academics. Pay parity has been maintained between clinical academics and their NHS colleagues and the Department of Health recognises the importance of maintaining formal and informal links between the health and higher education sectors.

71. Oncologists need to take part in research for a part of their training. Attention needs to be given to the provision of suitable research programmes in high quality research environments in which this training can take place and to which the trainees can contribute.

(z) There is widespread agreement that the poor state of the infrastructure for cancer treatment and research in the NHS is a serious barrier to clinical research. The Government must act quickly to address this through investment in the necessary staff, training, equipment and buildings (paragraph 91).

72. The NHS Plan sets out clearly the Government's aims for modernising the health service including investment in staff, training, equipment and facilities.

73. Cancer services, as a top priority for the NHS, will receive significant extra resources of £570 million a year by 2003/04. This will fund nearly 1,000 extra consultants in the six major specialties involved in cancer care by 2005/06 and more than 300 new pieces of equipment used in the diagnosis and treatment of cancer. These are in addition to the 46 linear accelerators and 332 items of breast screening equipment funded from the New Opportunities Fund, and the 120 CT scanners already being funded.

74. The NHS Cancer Plan sets out our goals and a timetable for improving cancer services across all these areas.

75. The Government is acting to improve the infrastructure for cancer research in the NHS through the creation of the NHS Cancer Research Network (see (n)).

(aa) We recommend that the Government ensures that ethical, safety and financial approvals for clinical trials are administered more effectively so that trials can proceed as quickly as possible after the submission of protocols. We believe that for multi-centre trials ethical approval from one of the MRECs should be sufficient. The Government should benchmark its performance in this area against other European countries (paragraph 95).

76. The Department of Health has recently established a new Central Office for Research Ethics Committees (COREC) which will advise on the changes necessary to speed up the process of ethical approval for research, and facilitate their implementation. A single ethical review by one MREC is now the norm. In this faster process, the safety and well being of the research participants must not be compromised. By facilitating training, COREC will act as a resource for researchers and for RECs to increase the quality of applications and thereby the speed the review process.

77. All relevant legislation and approved guidelines will appear as standards in the published Research Governance document. The draft Framework explicitly states that unjustified delay in procedures for obtaining ethical approval is itself unethical. The Department of Health is working with the industry on the action needed to ensure that a high proportion of proposals are approved without deferral, and that the approval processes are co-ordinated so as to work within a defined period.

78. The current procedure for ensuring safety approval for clinical trials, the Clinical Trials

Exemption (CTX) Scheme, was introduced in 1981. It was specifically introduced to ensure that clinical trials conducted in the UK could commence quickly while ensuring safety. It requires the Medicines Control Agency (MCA) to determine an application within 35 days, allowing a single extension of 28 days where supplementary data are required.

79. In the past 5 years the extension has been invoked in less than 10% of applications. The UK procedure is considered by the pharmaceutical industry to be very effective. A recent survey by the Association of the British Pharmaceutical Industry (ABPI) across 24 of its member companies indicated that there were no problems with the regulatory process.

EPIDEMIOLGY AND PUBLIC HEALTH RESEARCH

(bb) We agree with the London School of Hygiene and Tropical Medicine: "Cancer registration in the UK is too valuable as a public health resource for its organisation and funding to continue in their current haphazard fashion: this is the result of historical accident rather than strategic planning" (paragraph 98).

80. Cancer registries will be effectively supported and where necessary strengthened to enable them to contribute fully to the cancer modernisation agenda and to provide a clearer national picture of health and health inequality, related to cancer, so that changes over time can be assessed.

81. The Government will set out its plans to strengthen cancer registries, taking account of the Gillis review to which the Committee refers, early next year.

(cc) We recommend that, as a matter of urgency, the advisory group on patient confidentiality should address the concerns posed by the 1998 Data Protection Act regarding the registration of cancer (paragraph 109).

82. The creation of the proposed new advisory body for confidentiality and security has been delayed while consideration is given to how it would fit within the framework envisaged in the NHS Plan. The Department of Health is continuing to explore the issues involved in effectively supporting cancer registration, including any legislative measures that would achieve this goal.

(dd) We recommend that the Government should introduce legislation to make the registration of cancer a legal requirement, both to ensure the completeness of cancer registry data and to ensure access to those data for legitimate research purposes (paragraph 112).

83. The Government is determined to secure the future of cancer registration and will take the necessary action to ensure this.

(ee) We would welcome initiatives to extend research on the links between ethnicity, socio-economic conditions and cancer incidence and survival (paragraph 114).

84. This area has been identified as a priority for Department of Health research in line with the Department's wider efforts to combat inequalities in cancer survival.

85. The Economic and Social Research Council (ESRC) has funded a good deal of research into the relation between socio-economic factors – including ethnicity – and health and disease including cancer. The ESRC currently runs a major Research Programme on Health Variations. This work seeks to measure the differences in health, illness and outcomes across socio-economic factors and groups, and to examine the processes involved. The ESRC is currently considering further work in this field, and research in health remains a major priority for the Council.

86. The MRC has significantly expanded its general research into socio-economic and ethnic factors affecting health inequalities over the last three years, and also funds a large body of cancer epidemiology including the new "Million Women Study". The MRC recognises, though, that research into ethnic and social inequalities in cancer is as yet limited, compared to other areas. The MRC is exploring the opportunities to develop new studies.

RESEARCH INTO IMPROVING PATIENTS' QUALITY OF LIFE

(ff) We recommend that palliative care research should be conducted as a complement to research into cancer treatments and should receive Government funding (paragraph 117).

87. Palliative care research has been, and continues to be, a significant part of the Department of Health's cancer research portfolio. Two of the NHS National Cancer R&D Programme's twenty five priority areas concerned palliative care, and several projects were commissioned in response. Palliative care has recently been identified again as a priority for NHS research and development. Plans for the NCRN state clearly that palliative care trials will be an integral element of the NCRN trial portfolio.

88. The MRC will accept funding proposals in this area, and already supports basic and applied research in pain relief.

PATIENT INVOLVEMENT IN CANCER RESEARCH

(gg) We recommend that all Government-supported cancer research committees include patients' representatives as full members and that the Government provides resources to ensure proper training and support for patients' representatives (paragraph 119).

89. It is the Government's aim to build the patient's perspective into the research it funds. The Standing Group on Consumers in NHS Research advises the Director of Research and Development of the Department of Health on consumer involvement in all aspects of the NHS R&D programme. Its members have first-hand experience in involving consumers in health research and come from a wide range of disciplines. They include consumer advocates, researchers, clinicians, health and social service managers, and health information specialists.

90. The NHS R&D Health Technology Assessment (HTA) programme has for some time involved consumers in its work and is developing support for staff and consumers to work together. Consumers are members of the HTA advisory panels responsible for prioritising topics for commissioned research within the programme.

91. The Department of Health has funded The College of Health to undertake a three-year project titled "Voices In Action" which aims to create a sustainable training programme for user and carer representatives in the health service.

92. The MRC involves patient representatives in the planning of some clinical trials, and has formed a Consumer Liaison Group, composed mainly of lay members, as a subcommittee of Council, to advise on how patients and other stakeholders can be more involved in MRC decision making. The UKCCCR also has a consumer group which advises on UKCCCR trials.

INDUSTRY FUNDING

(hh) If the pharmaceutical industry is to be encouraged to do more cancer clinical trials in this country the costs of doing so must be made competitive with those in other countries (paragraph 129).

93. Industry members of the Pharmaceutical Industry Task Force Working Group on Clinical Research have drawn attention to competition between countries to run clinical trials. The three main parameters are speed (particularly start up times for research), cost and quality; the decision on placing research depends on a mix of these factors relevant to projects. The Working Group is developing an action plan to address all three parameters.

94. The establishment of the NCRN will greatly facilitate clinical trials. Pharmaceutical trials will be an important part of the NCRN trials portfolio.

(ii) We recommend that, as a matter of urgency, the MRC seek to understand better the ABPI concerns regarding Good Clinical Practice standards in MRC-funded clinical trials, and work with the NHS and the ABPI to find a resolution acceptable to all parties (paragraph 130).

95. There has been some confusion over the differences between Good Clinical Practice (GCP) as applied in industry and as applied in non-profit research. Both industry and the MRC work to the same International Committee for Harmonisation principles on GCP, aim to achieve the same scientific rigour, the same ethical codes, and the same protection for people participating in the trials. The only differences are in interpretation of the audit requirement, where standard industry practice involves much more active checking of the records and procedures of individual oncologists. The MRC places more emphasis on the need for prior independent review of the research question and design, and on training and supervisory frameworks, to avoid errors or fraud.

96. Adopting industry practices for all UK trials would greatly increase the costs of trials supported by cancer charities, the MRC, and the NHS, and would result in fewer trials being funded by the public sector. These trials generally differ from the kinds of trials run by industry for regulatory purposes. They are more likely to focus on long-term public health and quality of life outcomes, and to compare different kinds of drugs, or drug versus non-drug interventions.

97. However, the MRC and the ABPI agree that wherever a joint study is likely to be used for licensing purposes, it should conform to standard industry practice, to avoid any uncertainty about its acceptability for licensing purposes. Neither the MRC nor the ABPI are aware of any instances where this has presented problems in relation to MRC-funded trials. The MRC's GCP guidelines are widely used by non-MRC researchers, and when researchers are conducting trials sponsored mainly by industry they should normally adhere to industry standards.

98. The introduction of a research governance framework in 2001 will strengthen arrangements for ensuring the standards of clinical research in the NHS and academic sector.

99. The European Commission will be proposing further legislation on Good Clinical Practice following adoption of the draft Directive. The Medicines Control Agency will take the lead in developing a UK negotiating position, taking account the views of those affected, including the pharmaceutical industry and organisations which fund non-commercial clinical trials, for approval by Ministers.

GOVERNMENT FUNDING

(jj) We recommend that the MRC accelerate its procedures for assessing and approving phase III clinical trials (paragraph 133).

100. Approval for MRC phase III trials sometimes takes longer than approval from charities. However, cancer charities do not often play the lead role in evaluating and funding very large

trials. The MRC's role in managing large treatment and screening studies, which may involve investment of public funds of up to £10 million for any one study calls for more complex review procedures. The design of large trials needs to have the support of a high proportion of the relevant specialists, and the scientific and operational planning has to be meticulous.

101. The MRC will however review its procedures for any scope to streamline procedures. Over the past ten years the MRC has led the way in using trial development groups as part of its peer review, to raise the quality of proposals, and has also introduced new measures to ensure trials are ethical, and to help co-ordinate and prioritise applications. The quality and operational planning of applications from many centres has improved in recent years, and the formation of the NCRN should help others raise their standards. There may therefore be scope to simplify procedures for at least some applications, without lowering the quality of the study, or increasing the risks to participants.

(kk) The Government should increase funding for direct support of cancer research to at least a level to match that provided by research charities. We recommend annual expenditure dedicated to cancer research of at least £200 million per annum at current prices, not including funds from NHS R&D or the Higher Education Funding Councils (paragraph 134).

(pp) Most UK cancer researchers receive far more support from the research charities and the pharmaceutical industry than they do from the Government. We believe that this imbalance is unhealthy. Notwithstanding the Government's wish to partner and co-operate with cancer research charities, if it does not fund research then the research which it wishes to see will not be done. Cancer research charities cannot and should not be expected to fund research as part of a national strategy. The Government has abdicated its responsibility for cancer research and has by default placed the research agenda in the hands of charities and industry (paragraph 145).

102. As the Committee will recognise, comparisons of expenditure on cancer research are fraught with difficulty. For example, it is arguable that the MRC's cancer-related expenditure as a proportion of its total budget is broadly comparable to the National Cancer Institute's budget as a proportion of the total National Institutes for Health expenditure in the USA. The BBSRC, EPSRC, ESRC and the Natural Environment Research Council (NERC) all support research relevant to progress in understanding, detecting and preventing cancers (for example, in basic cell biology and medical engineering), though this is not always recognised. Similarly, comparisons between Government and charity expenditure rarely acknowledge the Government's substantial contribution to the infrastructure in which research is conducted, or the extent to which both the Government and the charities are supporting a wider range of basic research of potential relevance to more than one disease. The UK Government expenditure on cancer research is inevitably a smaller proportion of total expenditure from all sources than in many countries where a tradition of popular support for cancer research is less evident.

103. Nonetheless, the Government accepts the Committee's basic premise, and supports the case for increased investment in order to redress years of under-funding, to make the most of exciting new opportunities now flowing from leading edge research, and to ensure more effective take-up in the NHS. To summarise, relevant initiatives and related funding over the next three years will include:

(i) £1 billion Science Research Infrastructure Fund with the Wellcome Trust, building on the £750 million Joint Infrastructure Fund (JIF). JIF awards include capital equipment for a new Centre for Translational Cancer Research at the University of Cambridge School of Clinical Medicine, and over £3.5 million for a new building for Cancer Studies at the University of Southampton. In addition, The Wellcome Trust has made two very substantial, cancer-related JIF awards.

(ii) £250 million for new research supported by the Research Councils, with an emphasis on genomics. This also builds on the extra money which the Councils received following the Comprehensive Spending Review, including £12 million for the MRC to develop new DNA collections, with associated phenotypic, health and environmental information, as a national resource for research into multifactorial disease, including different forms of cancer.

(iii) By 2003 an additional £20 million each year from the Department of Health on the infrastructure for cancer research and an extra £4 million on prostate cancer research. This new funding will mean that for the first time the Government (through the Department of Health, the Higher Education Funding Councils and the Research Councils) will match the current investment of the voluntary sector.

(ll) The conviction of many witnesses and of those we met on visits is that most of the NHS R&D funding was disappearing into general support for NHS hospitals and that little of it was actually made available for research purposes. This means that of the £112 million that the Government claims to spend on cancer research, more than half is effectively unaccounted for and may not be spent on research at all. This situation is deeply unsatisfactory (paragraph 140).

104. Of the £112 million Government expenditure on cancer research, £63 million is based on estimates provided by NHS Trusts of the amount of NHS R&D Support funding they receive which is used to support cancer research.

105. R&D Support for NHS Providers ("Culyer funding") meets both NHS costs of supporting good quality R&D that is funded externally, and in appropriate cases pays for other research carried out in the NHS. New arrangements were announced in March 2000 that will target this funding more closely on providing the NHS base for high quality science and on the research priories and needs of the NHS. Under the new funding systems due to take effect from 1 April 2001, these two uses of NHS R&D funding will be separated to provide more transparency and improved accountability.

106. All recipients of R&D Support for NHS Providers have to account for their use of this funding in an annual report, and their performance is monitored by the NHS Executive. The allocation of separate funding streams for NHS Support for Science and for R&D for NHS Priorities and Needs mean that recipients will account for spending against more clearly defined objectives.

(mm) We recommend that decisions on NHS Support for Science awards include an element of scientific quality assessment as well as the proposed activity and cost model. We further recommend that awards are made directly to research groups rather than to NHS Trusts (paragraph 142).

(nn) We recommend that allocations of NHS Support for Science should be made in a way that permits an expansion in clinical research in both existing centres of research excellence and in emerging centres (paragraph 143).

107. NHS Support for Science allocations will be tied to eligible research grants that have an impact on NHS costs. The funding will reflect the requirements of research for infrastructure within the NHS organisations concerned. NHS R&D Funding is being developed to ensure that the appropriate clinical infrastructure is available within the NHS. For example, the NHS Cancer Research Network, announced in the NHS Plan, will build up high quality infrastructure for cancer research.

(oo) We recommend that annual NHS R&D funding for cancer research support be increased by £100 million immediately. This extra funding should be spread across the UK to ensure that approximately twelve large centres of cancer research excellence are developed, capable of delivering a volume of clinical research similar to or greater than that currently being delivered at the Royal Marsden Hospital. These centres and associated units should be closely linked with basic and translational cancer research laboratories (paragraph 144).

108. There are already a number of centres of research excellence in cancer in the UK involved in clinical research. The Government's plans for the NHS Cancer Research Network will substantially increase investment in the infrastructure for clinical research. By 2003 we will be investing an additional £20 million each year in this new infrastructure, which will provide a more comprehensive framework for clinical trials to be taken forward. The NCRN will be fully implemented by 2004, and its initial aim is to double the total number of cancer patients entering trials within three years.

109. The Department of Health has also announced that it will increase directly funded prostate cancer research by an additional £1 million for each of the next three years so that by 2003/04 the annual spend will be £4.2 million.

110. The NHS Cancer Research Network and the National Cancer Research Institute (see (uu)) will be considering the way forward with regard to Translational Research Centres.

CO-ORDINATION IN CANCER RESEARCH

(qq) We recommend that the chairman of the CRFF be a highly respected clinical scientist with policy experience who operates independently of the secretariat provided by the MRC. We also recommend that CRFF membership is widened to include representatives of the pharmaceutical and other related industries (paragraph 149).

111. The CRFF was set up following the No.10 cancer seminar to bring together the main public funders of cancer research to help improve co-ordination. It is currently chaired by Professor Sir George Radda FRS, Chief Executive of MRC, who is a highly respected scientist in the field of basic and clinical imaging. The Forum members have agreed that Chairmanship should rotate between government funded and charitable sectors every two years, and that the secretariat should be provided by the organisation to which the chairman belongs, to ensure efficient co-ordination.

112. One of the aims of the Forum is to strengthen links between funders, and this aim is more likely to be achieved by sharing responsibilities between members than by introducing an independent chair, without links to any of the funders.

113. The full range of industry's interests in cancer research cannot be represented by a single official, especially since most pharmaceutical companies, and many biotechnology companies are now truly multinational. The Forum has agreed that industry scientists and representatives will be invited to participate in projects and debates on a case by case basis, choosing the experts most appropriate to the issues.

SETTING STRATEGIES AND PRIORITIES IN CANCER RESEARCH

(rr) We recommend that a cancer research strategy should become an integral part of the National Cancer Plan which is to be published shortly. This strategy should be developed in consultation with cancer patients, research funders, and research practitioners, including relevant sectors of industry. The Research Plan should: have as its objective a reduction in

cancer incidence and mortality and an improvement in outcomes for cancer patients, in terms of successful treatment and quality of life; include a long-term blueprint for the required organisational structures and funding; cover the delivery of high quality basic, translational, public health and clinical research, and address research into the causes, nature, prevention, detection and treatment of cancer and palliative care (paragraph 151).

114. Research is identified as a key component in the NHS Cancer Plan, which addresses many of the areas highlighted by the Committee. The momentum will be sustained through our proposals for a National Cancer Research Institute (for which see the response to recommendation (uu)).

A NATIONAL CANCER INSTITUTE AND ACT

(ss) The twelve centres of cancer research excellence that we propose should each have a high level of clinical research activity and should have basic laboratory research and translational activities. Each research centre should be based in one of the cancer treatment centres currently being established under the Calman-Hine recommendations (paragraph 154).

115. The NHS Cancer Research Network will provide a framework for Cancer Treatment Centres to participate in clinical and translational research. The original proposal for the NHS Cancer Research Network recommended that it should include up to eight translational Research Centres. The Cancer Research Funders Forum is considering this particular recommendation in relation to the fact that many funders other than the Department of Health already fund active centres of translational research.

(tt) We are unconvinced that to select one of the UK's existing centres of cancer research excellence for development into a National Cancer Institute on the model of NCI in the United States, as suggested by some of our witnesses, would improve cancer research in the UK. The desired quality and volume of cancer research in UK can be better achieved by increasing substantially the investment in existing centres of excellence so that they can compete at the highest international level. These activities should be co-ordinated with visionary leadership and clear identification of national priorities, and subject to rigorous peer review (paragraph 155).

116. The Government agrees. Most evidence to the Committee appeared to oppose a new "bricks-and-mortar" National Cancer Institute.

(uu) We recommend the creation of a new National Cancer Research Institute to set national research priorities and to co-ordinate and fund cancer research in the UK. It should Co-ordinate cancer research in the UK by developing a cancer research strategy and identifying gaps in research funding; ensuring integration and complementarity between the Calman-Hine cancer care networks and research networks, and assuming the responsibilities of the UKCCCR and the CRFF in order to reduce unnecessary duplication of effort; Set priorities for clinical research; Set and implement priorities for cancer registration strategy by Managing and funding the National Cancer Registry, and Co-ordinating and funding regional cancer registries; Determine and set out the case for appropriate levels of Government funding for cancer research; Receive all Government funds for cancer research and allocate them to extra-mural research programmes and projects, on the basis of appropriate mechanisms of peer review; Make available assistance in peer review to charities funding cancer research; Produce and maintain Good Clinical Practice guidelines and oversee adherence to them; Provide guidance and co-ordinate training for oncologists; Issue and maintain guidance, subject to regular review, on the diagnosis of malignancy in

general practice; Co-ordinate the provision of appropriate tumour, tissue and serum depositories for cancer research, and Communicate with the public on issues related to cancer.

The National Cancer Research Institute should operate at arm's length from Government under the authority of its own Royal Charter, accountable to Parliament through the Minister for Science. We do not envisage it as a large organisation but as a small authority with a physical existence. It should not have its own intramural research programme, other than through the cancer registries, nor should it be based in an existing research facility (paragraph 156).

(vv) We recommend that the Government introduce a National Cancer Research Bill to: establish the National Cancer Research Institute and to place its funding on a statutory basis; set out the goals, objectives and functions of the National Cancer Research Institute, and place the registration of cancer and pre-cancerous diagnoses on a statutory footing (paragraph 157).

117. The Government accepts the need to improve cancer research strategy and co-ordination significantly. The NHS Cancer Plan announced that the Department of Health Director of Research and Development and the National Cancer Director have been asked to work with all those involved in the funding and delivery of cancer research and then to come forward with definitive proposals for a National Cancer Research Institute (NCRI). The NCRI will provide the focus for cancer research conducted across the country, and will have strategic oversight of that research. The NCRI will be a partnership between Government, the voluntary sector and the private sector. It will take the lead in identifying areas where further research initiatives are needed and most likely to lead to progress.

118. One of the key tasks for the NCRI will be to co-ordinate research into cancer genetics funded by Government, charities and industry. This country should be at the forefront of this rapidly evolving area.

119. The Government does not favour a model of research funding that would separate cancer research from all other areas of medical research and create a new funding agency. In the UK the MRC is the Government's principal agency for supporting biomedical research. It is the MRC's responsibility to decide the funds it devotes to cancer research as part of a balanced and comprehensive programme addressing the needs and opportunities arising across diseases and medical conditions generally.

120. In taking this view the Government acknowledges that there may, nonetheless, be useful lessons to be learnt from other models, and it will want to take these into account in taking forward its plans for cancer research. It is grateful to the Committee for drawing the Government's attention to the issue, and for the detailed exposition of the case for a NCRI in the Committee's report and supporting documentation.

121. Many of the other activities recommended that do not relate to research are already being effectively undertaken by other agencies and we are working to address all of them through the NHS Plan and the NHS Cancer Plan.

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